Overview of Personal Health Records

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Under auspices of:

CONNECTING FOR HEALTH℠

MARKLE FOUNDATION   *A Public-Private Collaborative*

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PHIN

The Challenge

Preventable Errors in Hospitals Kill 44,000 to 98,000 People Each Year

— (IOM)

More than 57,000 Americans die needlessly each year because they do not receive appropriate care

— (NCQA)

U.S. Adults Receive Barely Half of Recommended Care

— (McGlynn et al)

U.S. healthcare spending higher, but quality lower, compared with other industrialized countries

One-third of the $1.6 trillion spent on healthcare each year is wasted on duplicative or ineffective care

— (CECS at Dartmouth)

Scope of the U.S. Healthcare System

- ▶ **5500 hospitals**
- ▶ **700,000 physicians – 70% in small groups of < 10**
- ▶ **2 million nurses**
- ▶ **1800 health insurers**
- ▶ **6 million employers**
- ▶ **50 state Medicaid programs**
- ▶ **EVERY ONE DIFFERENT! NO RULES… no one in charge**

IOM's Six "Aims" for U.S. Health Care

▶ **Safe**—avoiding injuries to patients from the care that is intended to help them.

▶ **Effective**—providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse, respectively).

▶ **Patient-centered**—providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.

▶ **Timely**—reducing waits and sometimes harmful delays for both those who receive and those who give care.

▶ **Efficient**—avoiding waste, including waste of equipment, supplies, ideas, and energy.

▶ **Equitable**—providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

IOM's Ten "Design Rules" for U.S. Health Care

1. Care based on continuous healing relationships.
2. Customization based on patient needs and values.
3. The patient as the source of control.
4. Shared knowledge and the free flow of information.
5. Evidence-based decision making.
6. Safety as a system property.
7. The need for transparency.
8. Anticipation of needs.
9. Continuous decrease in waste.
10. Cooperation among clinicians.

The "Design Rules" that depend on patients

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The Politicians' Perspective

"To protect patients and improve care and reduce cost, we need a system where everyone has their own personal electronic medical record <u>that they control</u> and they can give a doctor when they need to."

- President Bush

At American Association of Community Colleges Annual Convention April 26, 2004

"We should adopt the model of a 'personal health record' <u>controlled by the patient</u>, who could use it not only to access the latest reliable health information on the Internet but also to record weight and blood sugar and to receive daily reminders to take asthma or cholesterol medication."

- Senator Hillary Clinton

NY Times, April 18, 2004

Stages of health care transformation?

- Adoption of electronic health records

- Interoperability of electronic health records

- *Proliferation of personal health records*

- *Shift of control to patients and families*

- *Redistribution of technology to the patient and family*

- *Reallocation of roles, responsibilities and … money?*

Extent of Clinical IT Adoption – CDC estimates (3/05)

- ▶ Hospital Emergency Depts.   31%
- ▶ Hospital Outpatient Depts.   27%
- ▶ Physician Offices   17%
- ▶ Physician CPOE   8%

What will it take to increase adoption?

▶ Financial incentives to end-users ("business case")

- CMS

- Pay for performance/pay for use

- Adjustments to Stark

▶ Confidence in product stability, interoperability

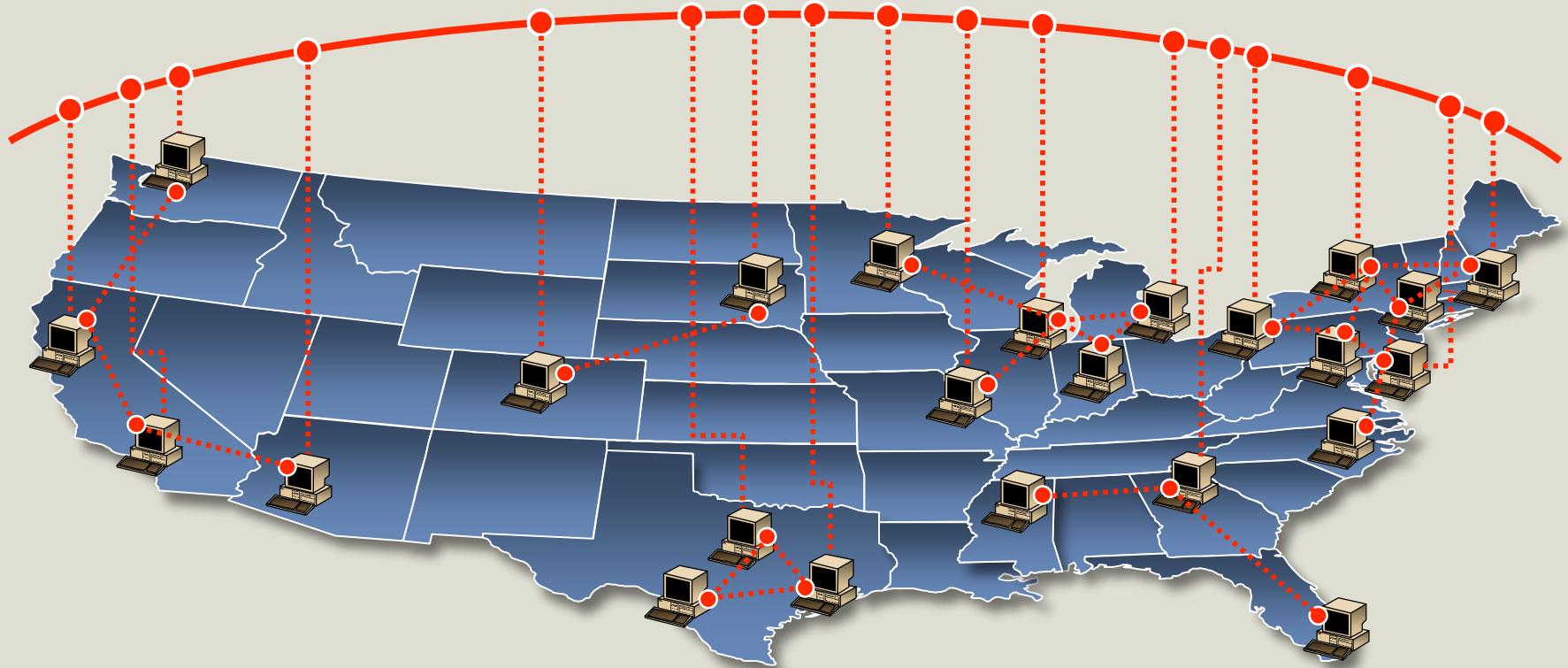▶ Cultural changes: MD, public

The interoperability assumptions

▶ A future of better, more efficient care can be accomplished through "dynamic connectivity" that allows information to move:

- Where it's needed

- When it's needed

- In a private and secure manner

▶ Achieving this goal will require public and private sector collaboration

▶ A 'roadmap' is needed to chart the course
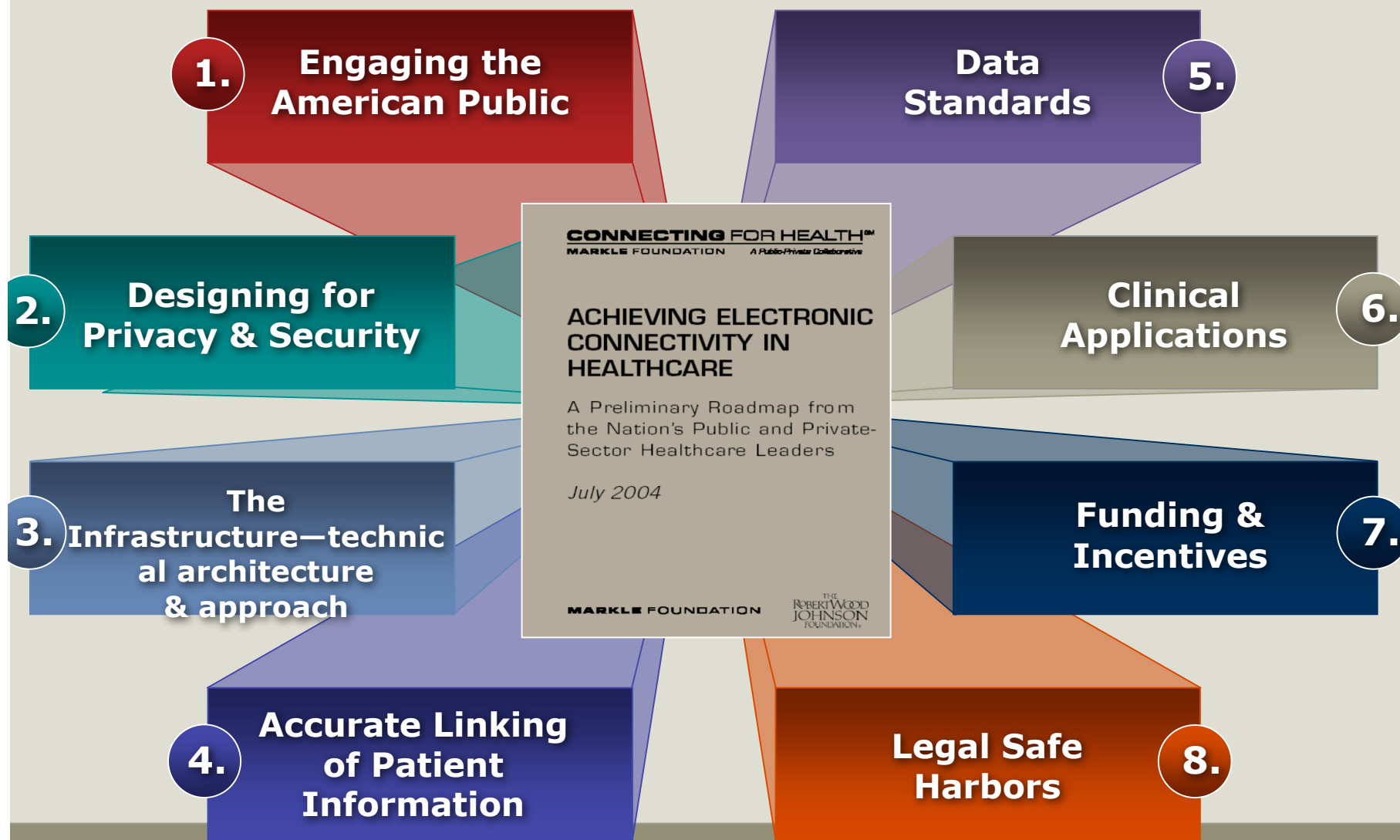
What is *Connecting for Health*?

- Broad-based, public-private coalition
- More than 100 collaborators
  - Providers (AMA, ACP, AAFP, ACEP, Presbyterian, Partners)
  - Patients (IAM, NCCS)
  - Suppliers (RxHub, Surescripts, J&J, Pfizer)
  - Payers (CAQH, AHIP, BCBSA, GE, Leapfrog, PBGH)
  - Accreditors (NCQA, JCAHO, URAC)
  - Government agencies (CMS, AHRQ, CDC, FDA, VA)
  - Researchers (AHRQ, CDC, AMIA)
  - IT vendors (Siemens, CSC, IBM, Microsoft, Allscripts)
- Founded and supported by **Markle Foundation**, with additional support from **Robert Wood Johnson Foundation**
- See **www.connectingforhealth.org**

Purpose of *Connecting for Health*

Catalyze changes on a national basis to create an interconnected, electronic health information infrastructure to support better health & healthcare

Eight Key Areas of Roadmap Recommendations

1. Engaging the American Public

2. Designing for Privacy & Security

3. The Infrastructure—technical architecture & approach

4. Accurate Linking of Patient Information

5. Data Standards

6. Clinical Applications

7. Funding & Incentives

8. Legal Safe Harbors

CONNECTING FOR HEALTH℠
MARKLE FOUNDATION   A Public-Private Collaborative

ACHIEVING ELECTRONIC CONNECTIVITY IN HEALTHCARE

A Preliminary Roadmap from the Nation's Public and Private-Sector Healthcare Leaders

July 2004

MARKLE FOUNDATION   THE ROBERT WOOD JOHNSON FOUNDATION

Principles of the Connecting for Health *Common Framework*

▶ Safeguards privacy

▶ Built without a national patient ID

▶ Leverages both "bottom-up" and "top-down" strategies

▶ Builds on existing systems ("incremental")

▶ Consists of an interoperable, standards-based "network of networks" built on the Internet

▶ Patient information remains where it is now and is not kept in a central database ("decentralized")

▶ Data-sharing initiatives have local autonomy but follow certain **standards and policies** to enable interoperability ("federated")

What is a "Personal health record"?
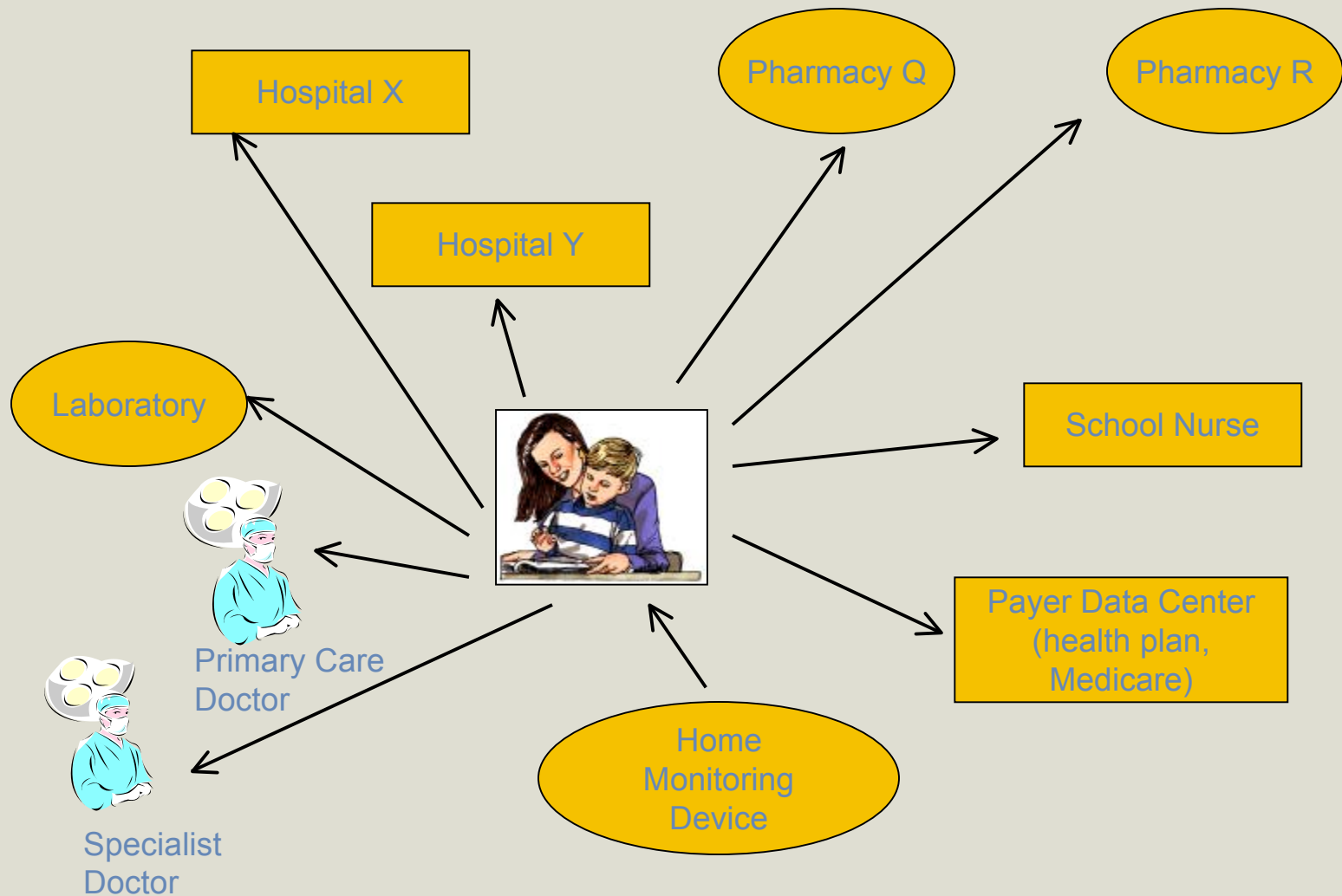
- No good answer today

- Some of its attributes:

    - Person controls own PHR

    - Contains information from entire lifetime

    - Contains information from all providers and self

    - Accessible from any place, at any time

    - Private and secure

    - Transparent – strong audit trail

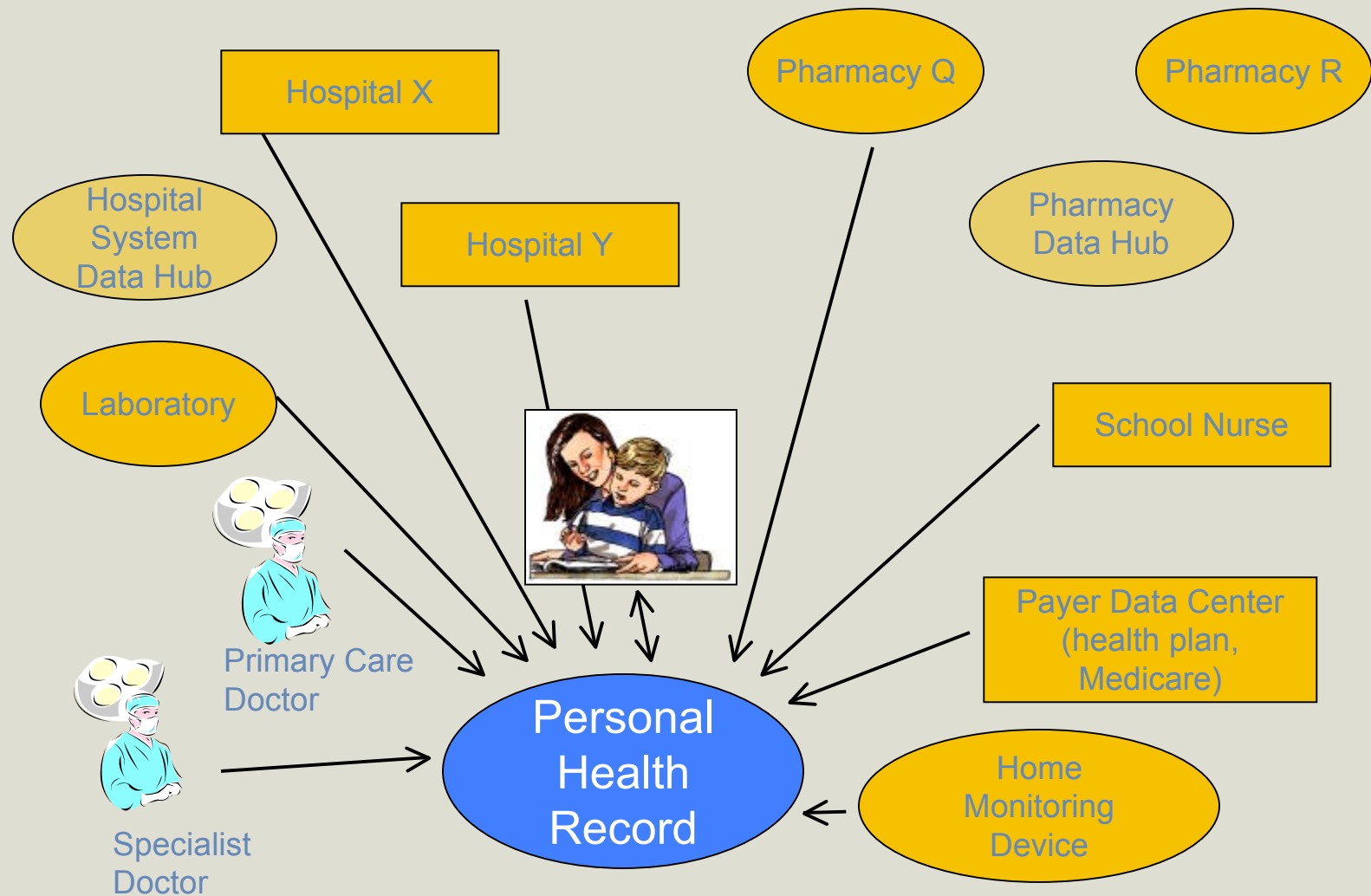   - Interactive across one's health care network

Potential of Personal Health Records

▶ Giving individuals access to and control over their personal health information enables:

- Patients better able to maintain health and manage their care

- More reliable care; e.g., in emergency situations

- Greater efficiency, less duplication of tests and quicker access

- Improved satisfaction, lower cost and greater choice

- Improved health care quality and safety

- More effective communication and collaboration between patients, doctors, pharmacies, and others

Retrieving your health information

Hospital X

Hospital Y

Pharmacy Q

Pharmacy R

Laboratory

School Nurse

Primary Care Doctor

Specialist Doctor

Home Monitoring Device

Payer Data Center (health plan, Medicare)

The Person as an Information Hub

Hospital X

Hospital System Data Hub

Hospital Y

Pharmacy Q

Pharmacy R

Pharmacy Data Hub

Laboratory

School Nurse

Primary Care Doctor

Payer Data Center (health plan, Medicare)

Specialist Doctor

Personal Health Record

Home Monitoring Device

Environmental Scan

▶ EHR vendors are increasingly offering patient portals, and they continue to be rolled out by providers

▶ Some models that are unconnected to EHRs have other interesting connectivity:

  ▪ WebMD's importation of claims

  ▪ Medem's new product, which can be stand-alone or offered by the physician

  ▪ Cerner diabetes initiative

  ▪ Health plans, PBMs and retail pharmacies all have member/customer access applications with PHR-like functions

▶ Increase of device offerings (e.g., USB-based, moipod, cell phones, smart cards, FDA approval of Health Buddy®)

Who would use a PHR?

Over two-thirds would use PHR features if available

Based on responses to the question, "If you could keep your medical records online, which of the following would you do?"